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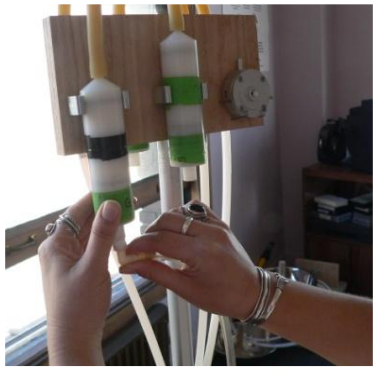


RESEARCHING THE ENVIRONMENT AND WOMEN'S HEALTH

# Pollution Gets Personal

## Reporting Exposures to Study Participants

Julia G. Brody, PhD

March 2012

# Agenda

## Reporting exposures to participants

- Why?
- How?
- What happens?
  - Experiences of study participants
- Recommendations and questions

# Personal Exposure Report-back Ethics (PERE) Study

Julia Brody, Ruthann Rudel, Phil Brown, Jessica Tovar, Rachel Morello-Frosch, Shaun Goho
Silent Spring Institute, Brown University, CBE, UC Berkeley, Harvard Law School

- 5 peer-reviewed articles
- 2 NIEHS and 2 NSF grants
- Consultations with numerous other studies
- Workshop for 40 researchers, study participants, advocates, ethicists

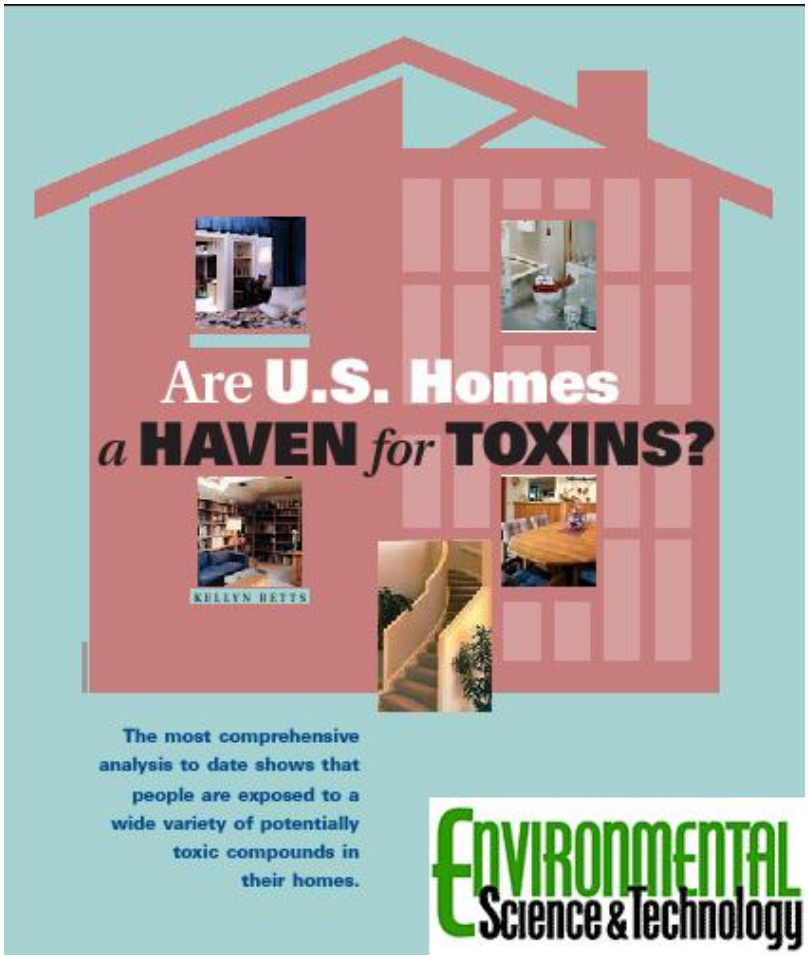
# Reporting personal exposures

- **Why?**

# For emerging contaminants

- **Early exposure measurements precede knowledge of…**
  - Human health effects
  - Sources

    *"None of these chemicals come with a return address."*
  - Toxicity, mechanism of action




*Rudel et al., ES&T 2003; Brody et al., AJPH 2009; Rudel et al. ES&T 2010*

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# CBPR values: Partnership

- Mutual respect, open communication
- Collaboration to address community issues
- Build community capacity
- Knowledge is power
- Co-learning
- Co-ownership of data

# Emerging contaminants: Clinical model doesn't fit

- Expert-driven (doctors decide) but medical providers aren't the experts
- Response isn't medical
- Drawbacks when science is uncertain
  - Problems when knowledge evolves
  - Limits participants' learning and action
- Medical practice has evolved

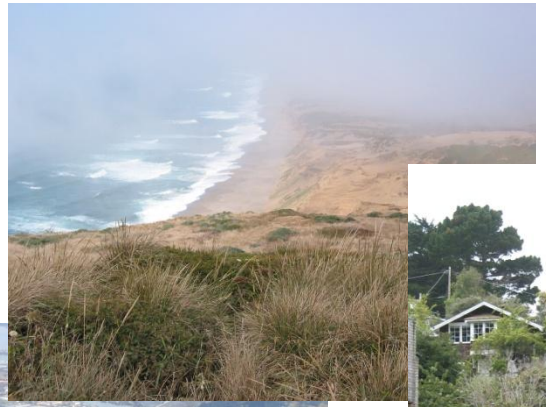
# Human research ethics criteria

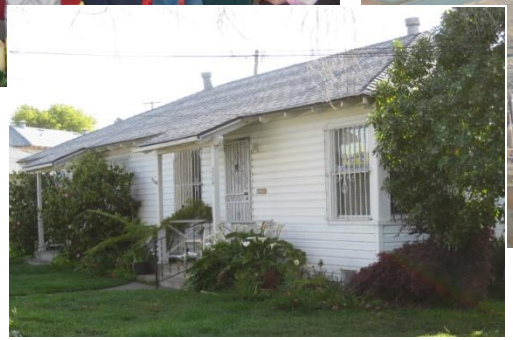
- **Autonomy, respect for persons**
  - Right to know or not know
- **Justice**
  - Information disparity / power disparity
- **Minimize harm**
  - Emotional distress
  - Ineffective action
  - Stigma
  - Expense, legal effect
- **Maximize benefit**
  - Informed action
  - Environmental health literacy
  - Validate health concerns

- **Report-back methods**

# Household Exposure Study

- 170 homes





# Data

- > 100 analytes
- Indoor, outdoor air
- Dust
- Urine, some blood
- Observation
- Self-report

# Report-back methods

- **Individual data**
  - Informed consent
    - Set expectations: What can the study say?
    - Right  to know or not know
  - Written report:  text and graphs, contextw
  - Access to researcher by phone or in-person
  - Exposure reduction resources
- **Aggregated data**
  - Fact sheet, community meetings, news media, web

# Individual report-back

- Multi-level
- What we know/don’t know
- Community and individual exposure reduction

# Is It Safe?

## Descriptive

- ★ What did you find?
- ★ How much?

## Analytical

- Is that high?
- Is it safe?
- Where did it come from?

## Recommendation

- What should I do?


*Brody et al, 2007, AJPH*

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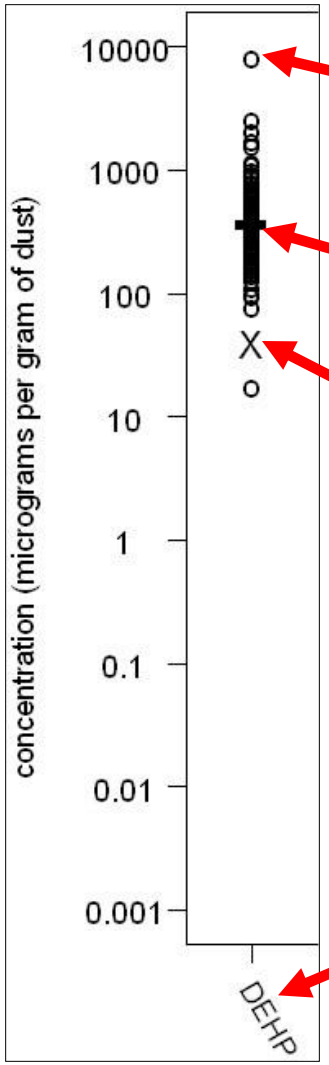
# Report-back packet

- Cover letter
- Text summary of individual results
- How to read … individual results graphs
- Individual results graphs
- How to read … community-level graphs
- Community-level results graphs
- Background:  chemicals, sources
- Exposure reduction alternatives

# Narrative excerpt

- “We detected many chemicals in every home in the study”
- “One of the chemicals we found in your urine is a weed killer…. If you are using a weed killer in your yard, you could reduce your exposure by controlling weeds without these chemicals.”
- “We are studying this chemical because….”

# How to read your results




**Each o represents one other home in the study**

**– is the sample from your home**

**X is the EPA Guideline**

DEHP common uses: Plastics, inks, insect repellant, cosmetics, rubbing alcohol, liquid soap, detergents, lacquers, munitions, industrial lubricant.

**Chemical abbreviation (di(2-ethylhexyl) phthalate)**

**Brody et al. *AJPH*, 2007**

## Part 2: Pesticides in Urine  Summary of Your Results

Pesticides are chemicals used to kill bugs, weeds, and other pests. We tested for 9 pesticides. We tested 85 mothers. We did not test babies for pesticides.

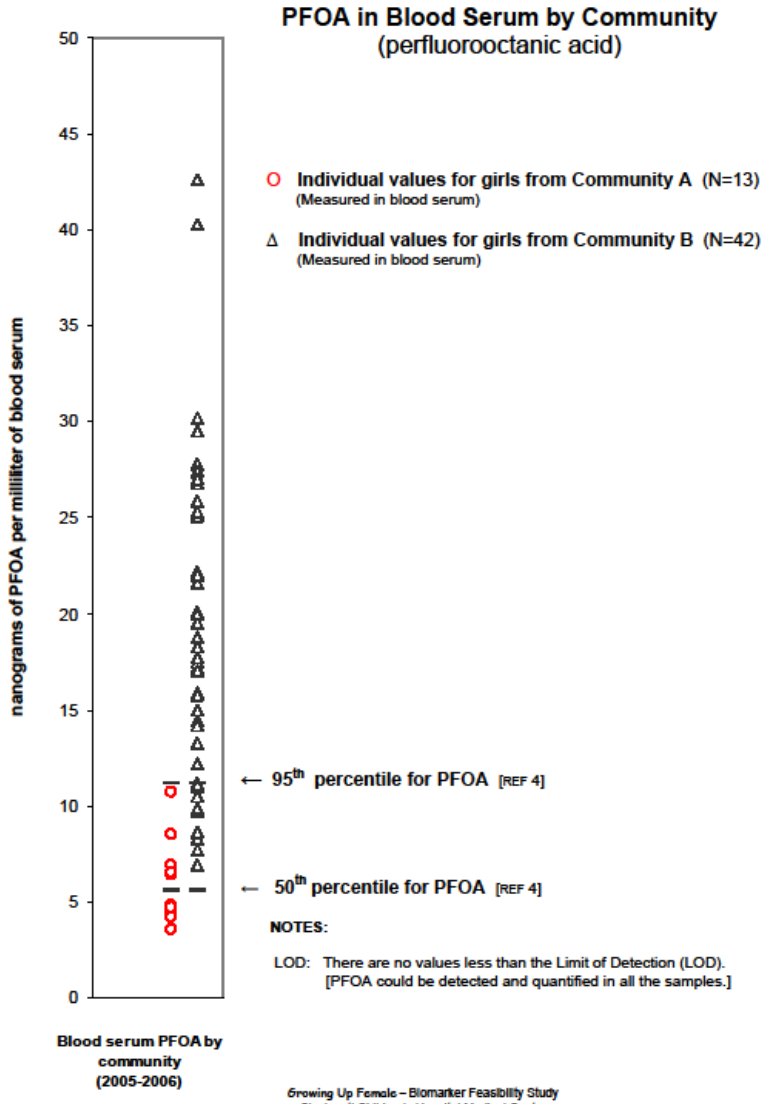
**Your Pesticide Results:** We found 6 pesticides in your urine sample. We found pesticides in most mothers we tested. You can use the Results Chart on the next page to compare your pesticide levels to the average (most common) levels for pregnant women in the U.S. The attached List of Chemicals Tested gives more information about each chemical tested.

| Pesticides are commonly found in | Possible risks to people | Possible ways to reduce exposure |
|---|---|---|
| ▪ Bug and weed killers used in homes, yards, farming, and landscaping.<br>▪ Insect repellants.<br>▪ Products to kill head lice.<br>▪ Products to kill fleas on pets.<br>▪ Termite and mosquito control. | ▪ Some pesticides can affect hormone systems, reproduction, and brain development.<br>▪ Some pesticides can affect the kidneys and liver.<br>▪ Some pesticides can cause cancer. | ▪ Control indoor and outdoor pests with less toxic methods, such as bait traps.<br>▪ Wash fruits and vegetables. California tests samples of fresh produce for pesticides and takes action if the amounts are too high. For even less exposure, you can buy "certified organic" or "pesticide free" produce. |

**For More Information**

Biomonitoring California www.biomonitoring.ca.gov
CDC National Biomonitoring Program www.cdc.gov/biomonitoring

**If you have any questions, please call the Project Coordinator, Jackie Schwartz, at 510-986-8925.**




# Cincinnati BCERC

Used our model to report on PFOA

Source: Susan Pinney, Katie Brown, Ann Hernick

# Community report-back

- Neighborhood meetings


Research

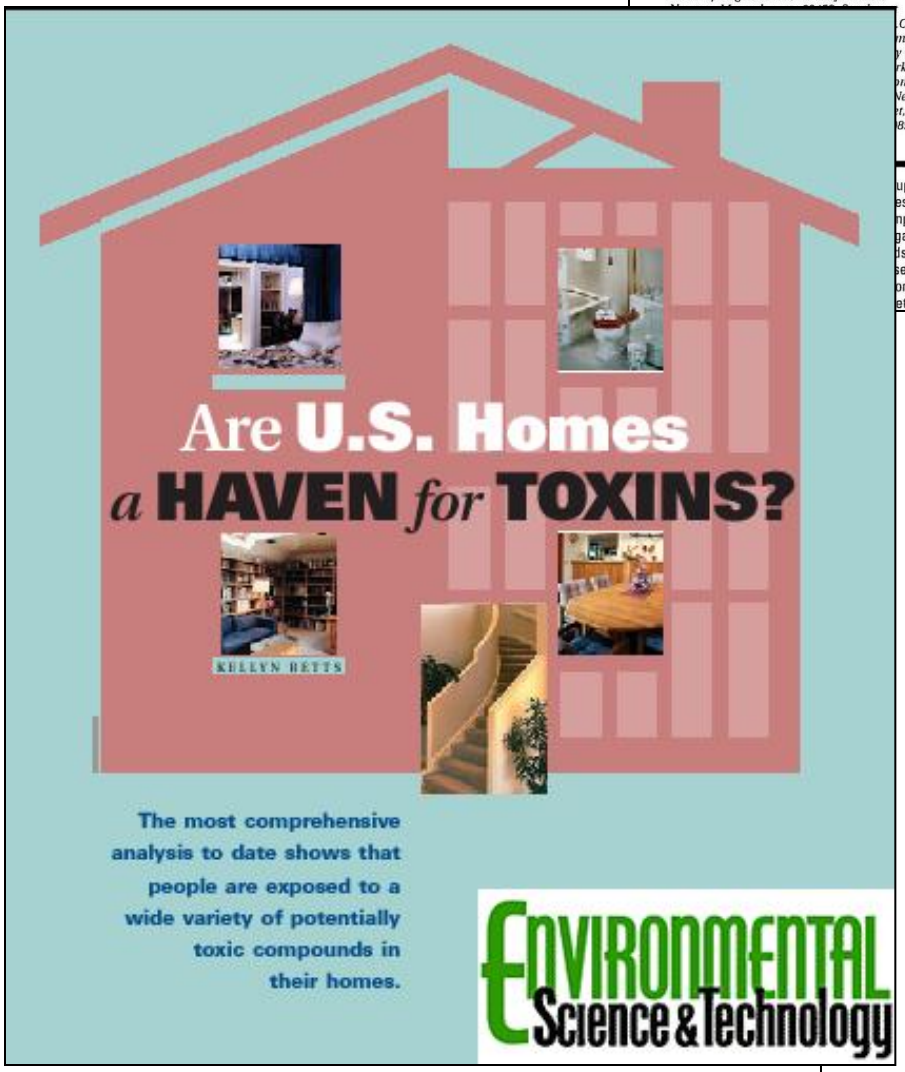
# Phthalates, Alkylphenols, Pesticides, Polybrominated Diphenyl Ethers, and Other Endocrine-Disrupting Compounds in Indoor Air and Dust

RUTHANN A. RUDEL,*,† DAVID E. CAMANN,‡ JOHN D. SPENGLER,§ LEO R. KORN,∥ AND JULIA G. BRODY†

*Silent Spring Institute, 29 Crafts Street,*

## Introduction

Current widespread interest in a range of health effects potentially associated with endocrine-disrupting compounds (EDCs) has made exposure assessment for these compounds a priority. Studies of potential health effects associated with EDCs have been hampered by lack of information about the major sources of exposure to EDCs. Furthermore, because many EDCs act additively through a common mechanism of action or have antagonistic or other interactive effects by operating at different points in cell signaling systems,




Environmental Health

BioMed

Research

Open Ac

## PCB-containing wood floor finish is a likely source of elevated PCBs in residents' blood, household air and dust: a case study of exposure

Ruthann A Rudel*[1], Liesel M Seryak[2] and Julia G Brody[1]

Address: [1]Silent Spring Institute, 29 Crafts Street, Newton, MA 02458, USA and [2]Division of Environmental Health Sciences, College of Public Health, The Ohio State University, 320 West 10th Ave., Columbus, OH 43210, USA

Email: Ruthann A Rudel* - rudel@silentspring.org; Liesel M Seryak - Seryak.2@OSU.edu; Julia G Brody - brody@silentspring.org

* Corresponding author

*Environ. Sci. Technol.* **2008**, *42*, 8158–8164

## Elevated House Dust and Serum Concentrations of PBDEs in California: Unintended Consequences of Furniture Flammability Standards?

AMI R. ZOTA,*,†,‡ RUTHANN A. RUDEL,† RACHEL A. MORELLO-FROSCH,§ AND JULIA GREEN BRODY†

*Silent Spring Institute, Newton, MA, Department of Environmental Health, Harvard School of Public Boston, MA, and Department of Environmental S and Management and School of Public Health, U California, Berkeley, Berkeley, CA*

*Received June 27, 2008. Revised manusc August 7, 2008. Accepted August 11, 2008.*

Studies show higher house dust and body burde PBDE flame retardants in North America than Eu is known about exposure variation within North A where California's furniture flammability standard use. We compared dust samples from 49 homes California communities with 120 Massachusetts h with other published studies. Dust concentrations [n ng/g] in California homes of BDE-47, -99, and -100 (112-107 000), 3800 (102-170 000), and 684 (<MRL- respectively, and were 4−10 times higher than p reported in North America. Maximum concentrati highest ever reported in indoor dust. We then inv whether human serum PBDE levels were also highe compared to other North American regions by ar 2003−2004 National Health and Nutrition Examina (NHANES), the only data set available with serum representative sample of the U.S. population ($n = 20$ residence was significantly associated with nearl higher ΣPBDE serum levels [least square geomet (LSGM) ng/g lipid, 73.0 vs 38.5 ($p = 0.002$)]. Elevat exposures in California may result from the state' flammability standards; our results suggest the ne research in a larger representative sample.

with Europe (*3*, *4*). Regional variation within the U.S. may result from more stringent furniture flammability standards in California than in other states; however, this possibility has not been evaluated.

Three major PBDE commercial mixtures have been commonly used in consumer products: deca-BDE, octa-BDE, and penta-BDE (*5*). Penta-BDE has been most often mixed into polyurethane foam (PUF) used in furniture, while octa- and deca-BDE are used in electronics and other plastic products (*6*). Penta-BDE is typically about 3−5% by weight in treated foam, and is easily liberated into dust because it is not chemically bound to the foam product. Penta-BDE has been used almost exclusively in the U.S (*6*) and mostly in furniture for sale in California in order to comply with

## Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure*

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*University of California at Berkeley*

JULIA GREEN BRODY
RUTHANN RUDEL
*Silent Spring Institute*

PHIL BROWN
MARA AVERICK
*Brown University*

Journal of Health and Social Behavior 2008, Vol 49 (December): 417–435

*We report on interviews conducted with participants in a novel study about envi-*

# Community report-back

- News media


bodywise

Is Your Furniture Making You Sick?

Toxins can hide in bookcases, shower curtains, and old clocks. Scary, but protecting yourself is simple.

An antique clock topples in a Southold, New York, living room, and the pendulum cracks, soaking the carpet with two cups of liquid mercury—a potent neurotoxin.

Inside 120 Cape Cod homes, scientists find more than 60 chemicals that interfere with hormones and may be linked to behavioral problems, obesity, diabetes, and cancer. The hormone disruptors are in house dust and in the air and include chemicals in plastics and detergents. A major source is the furniture. You may know to test vintage furniture for lead paint, but that's not the only place toxins hide.

■ ANTIQUE CLOCKS, MIRRORS, BAROMETERS, THERMOMETERS, AND LAMPS

**Hidden toxin:** Mercury, used to weight clock pendulums and lamp bases, to provide a reflective surface behind the glass of old mirrors, and to indicate pressure and temperature changes in barometers and thermometers.

**Health threat:** Inhaled mercury vapors, which are odorless, can cause shortness of breath, chest pain, nausea, vomiting, diarrhea, and high blood pressure.

and use an eyedropper to suck up droplets one by one. Place in a ziplock bag, then double-bag—and call your local health department about how to dispose of it and the clothes. For large or hard-to-clean spills, find an environmental or hazardous materials contractor or engineer in the yellow pages. "Never sweep mercury with a broom—the mercury will adhere to broom bristles and dust pan surfaces and spread every time you use them again," warns Wanda Lizak Welles, PhD, chief of hazardous substances events surveillance for the New York State Department of Health. Vacuuming is even worse. "As the vacuum cleaner motor warms up, you'll shoot mercury vapor into the air with the machine's exhaust." For detailed cleanup instructions, go to www.health.state.ny.us/environmental/chemicals.

Wash permanent-press fabrics before you use them to reduce chemicals.

■ SHOWER CURTAIN LINERS, PLASTIC TABLECLOTHS, OTHER SOFT, FLEXIBLE PLASTICS

**Hidden toxin:** Phthalates, the soft, flexible plasticizers found in everything from shower curtains and tablecloths to the coverings on some beanbag chairs.

**Health threat:** Studies suggest that phthalates are hormone disruptors.

and low sperm quality in men."

**What to do:** "Avoid them," Rudel says. "If something has that plasticky, new-car smell, it probably contains phthalates. If you can smell it, you're breathing it in. If you buy something and discover it has this smell, open the windows to air out your home and take the product outside. Let it sit there until the smell goes away. Sunlight breaks down chemicals faster."

■ PRESSED-WOOD FURNITURE AND PERMANENT-PRESS FABRICS

**Hidden toxin:** Formaldehyde, found in the adhesives in particleboard, plywood, and medium-density fiberboard (MDF). Also in the finish of permanent-press fabrics.

**Health threat:** A known human carcinogen, formaldehyde is associated with nasal and brain cancers and possibly leukemia. Immediate reactions include eye irritation, skin and respiratory allergies, asthma, nausea, coughing, chest tightness, and wheezing.

**What to do:** Choose pressed-wood products made with phenol formaldehyde (PF) resin or methylene diisocyanate (MDI) resin—these emit less formaldehyde. A veneer or water-resistant coating will reduce


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LATEST NEWS [VRSN] VeriSign Q3 net loss $1.02 a share vs 6c profit

PRESS RELEASE

**Californians Have Toxic Flame R**
**Levels Twice the National Avera**
**Peer-Reviewed Study**
**State and Federal Governments Consider**
**Expand Use of Flame Retardants**


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CAPITOL WI

THE NEWSPAPER OF CALIFORNIA GOVERN

**Leno asks Governor to ban controversial fire retardants by executive order**

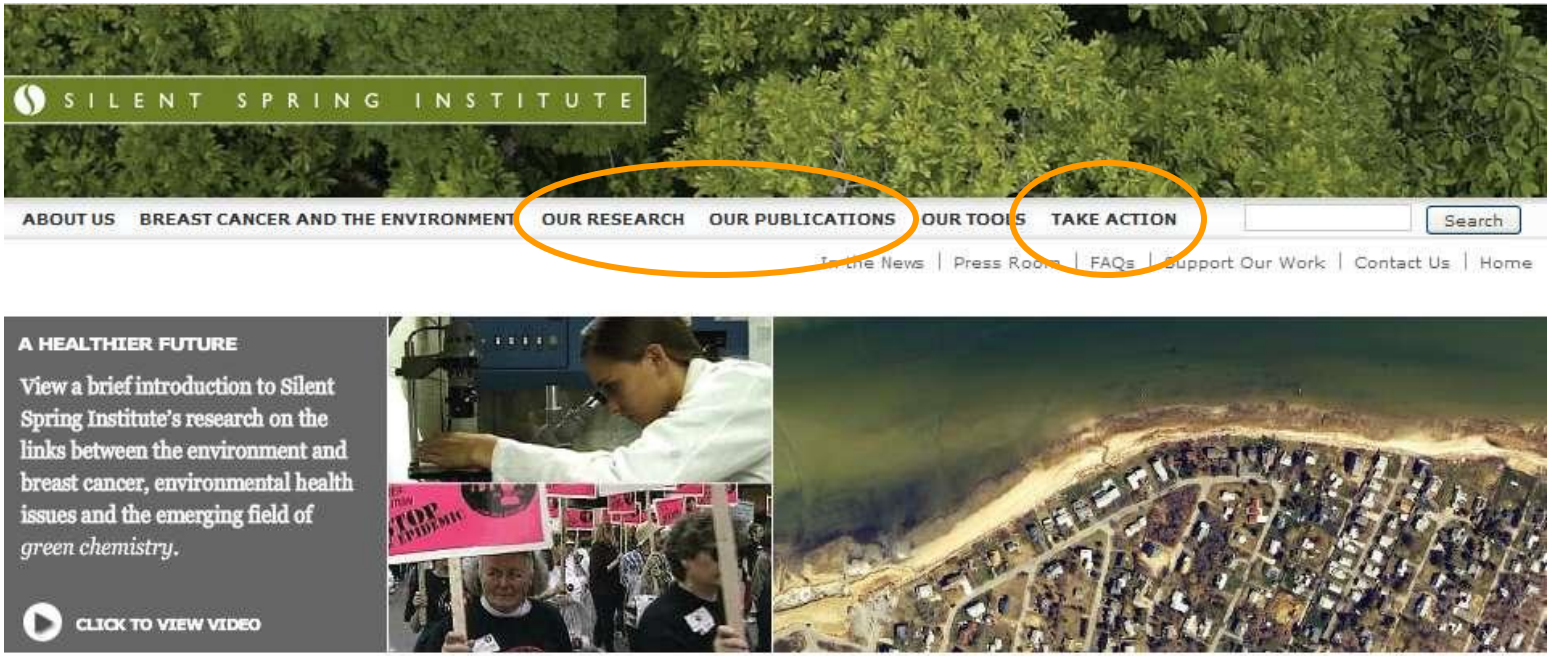

Californians have higher le
flame-retardant PBDEs in t

Researchers find that residents not only have more of the ch
than people elsewhere, but that levels in California homes ca

By Thomas H. Maugh II, Los Angeles Times Staff Writer
October 4, 2008

# Community report-back

- Online




**www.silentspring.org**

**www.cbecal.org**

# What can I do?

**Polluters**
(refinery, ships)

**Products**
***hard to avoid***
(flame retardant)

**Products**
***individual choices***
(indoor pesticides)

**Collective Action**

**Individual Action**

**Organize**

**Participate**

**Vote!**

**Chemicals policies**

**Consumer campaigns**

**Vote!**

**Product choices**

**IPM**

# Researcher responsibility to interpret

– **“You have to ‘titrate’ the message.”**

-- Susan Pinney

# Feedback from study participants

- Prototype reviews
  - COB - usability testing (Rachel Morello-Frosch)
  - CYGNET focus groups (Larry Kushi)
- Report-back experiences
  - Growing Up Female survey (Susan Pinney)
  - HES interviews (Julia Brody, Phil Brown, Rachel Morello-Frosch)

# Prototype reviews

- Reacted favorably
- Want to know
  - "More"
  - Results in comparison to other participants, national levels
  - Levels of health concern/benchmarks
  - Specifics about exposure reduction
- More people prefer graphs, some prefer text
- Want access to someone

# Prototype reviews

- Understand basics, including health uncertainty
- View results as family resource for future reference

# Experiences of our participants

## Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure*

REBECCA GASIOR ALTMAN
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*Silent Spring Institute*

PHIL BROWN
MARA AVERICK
*Brown University*

*Altman et al., 2008, Journal of Health and Social Behavior*

*Adams et al., 2010, Journal of Health and Social Behavior*

Journal of Health and Social Behavior 2008, Vol 49 (December): 417–435

*We report on interviews conducted with participants in a novel study about environmental chemicals in body fluids and household air and dust. Interviews reveal how personal and collective environmental history influence the interpretation of exposure data, and how participants fashion an emergent understanding of environmental health problems from the articulation of science and experience. To the illness experience literature, we contribute a framework for analyzing a new category of embodied narratives—"exposure experience"—that examines the mediating role of science. We update social scientific knowledge about social responses to toxic chemicals during a period in which science alters public understanding of chemical pollution. This article is among the first published accounts of participants' responses to learning personal exposure data, research identified as critical to environmental science and public health. Our findings raise the importance of reporting even uncertain science and underscore the value of a community-based reporting strategy.*

# Interviews with participants

- 50 participants
- 60-90 minutes, in-person
- Transcribed, coded in NVivo
  ….
- How do people assign meaning to their results?  Do they get the messages?
- What is their experience?
- Is there a public health benefit/harm?

# What did people learn?

- Many chemicals are detected in homes
- Banned substances are found today
- Many sources
- Comparisons to study distributions and EPA guidelines
- Common household chemicals are unregulated, understudied


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# Key experiences

- Participants wanted their results
- Increased trust in researchers
- Pride in contributing to science and health
- Dramatic conceptual shifts:  Pollution becomes personal
- Reflections on family illnesses
- Sense of “toxic trespass”

# Key experiences

- Frustration at information gaps
- Evolving interpretations, brainstorming
- Motivation to reduce exposure

# Differences across communities

- Expectations grounded in community history
- Shared surprises about indoor sources
- Struggle to gain control
  - Action or psychological distancing
- Individual vs. community action

- At first I was thinking, “God, I wish I didn’t know all this.” But the more I think about it, the more I understand it, the more I feel like it helps me to, … do whatever I can…if you know the information then you can’t not participate in trying to make change.

# Richmond community action contributed to court ruling on cumulative impact assessment!

# Researcher experiences

- Focus on understanding “high” results
- The temptation to reassure
  - “…there’s no evidence that…”
  - Outdated EPA guidelines
- Public health and good vs. bad worry
- Rethinking “health literacy” in light of
  - universal capacities
  - democracy

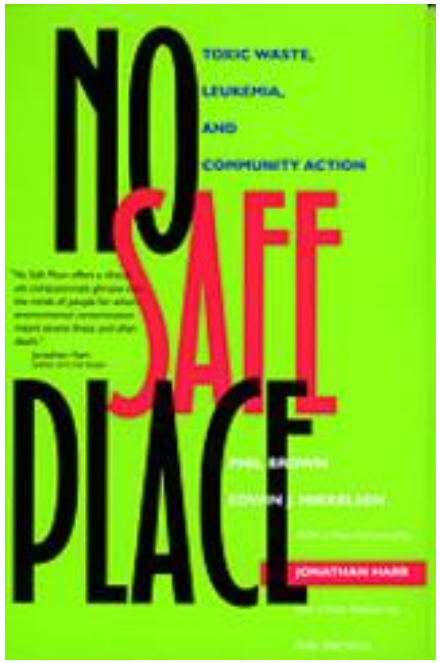
# Backdrop for report-back

**Psychology and sociology literatures on**

- Cognition and cognitive heuristics
- Stress and coping
- Social networks, social knowledge
- Risk communication
- Public understanding of science
- … more

# Backdrop for report-back

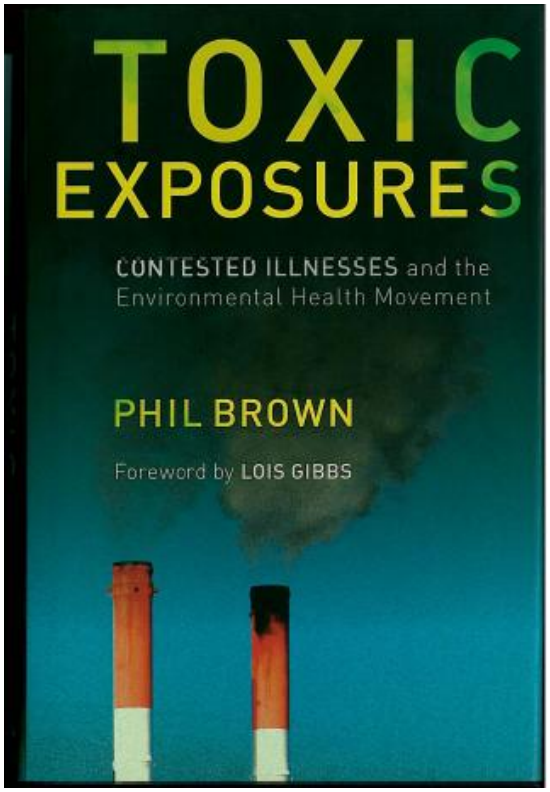
## Public responses to contamination




- Love Canal
- Three Mile Island
- Bhopal
- Chernobyl
- Woburn
- Katrina

*Brown and Mikkelson 1997*

# Backdrop for report-back




*Brown 2007*

- Embodied health movements
  - Breast cancer
  - Asthma
  - Autism, learning disabilities

# Recommendations

- Build on community partnerships
- Begin with “right to know …not know” in informed consent
- Set expectations for what studies can/can’t say about exposure and health
- Provide context to make individual results meaningful
- Address opportunities for action

# Recommendations

- Consider cultural context (of course)
- Respect multiple learning styles (verbal, graphic)
- Respond to unexpected or extreme results

# Challenges

- Timing
- Consensus on benchmarks
- Managing overload for the participant
- Automating processes for the researcher

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**A HEALTHIER FUTURE**

View a brief introduction to Silent Spring Institute's research on the links between the environment and breast cancer, environmental health issues and the emerging field of *green chemistry*.

CLICK TO VIEW VIDEO

*Silent Spring Institute researches the links between the environment and women's health, especially breast cancer.*

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Today's Environmental Health News

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## FEATURED RESEARCH

Tests find new contaminants in Cape Cod's drinking water supply

President's Cancer Panel highlights everyday exposures to environmental pollutants and cancer

Oil refinery toxics found in air of nearby hom

Researcher s call for better results reporting in breastmilk studies

Pollution from household and personal care products has been a blind spot for society, according to

## MEDIA COVERAGE

Household Exposure Study highlighted by the NIEHS' Gwen Collman, *The Environmental Factor*

Director of Research, Ruthann Rudel, participates in review of soy infant formula, *The Environmental Factor*

Chemicals Found in Area Drinking Water, *WCVB-TV*

Silent Spring water tests reveal contamination, *Cape Cod Times*

## NEW AT SILENT SPRING INSTITUTE

Massachusetts Environmental Trust funds Silent Spring Institute research by the sale of specialty license plates

Dinner honoree, Judi Hirshfield-Bartek, interviewed by *The Boston Globe*

upporters of this year' ends of *Silent Spring Institute Dinner*, May 6

## DID YOU KNOW?

Of the 3,000 high-production

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